DOCUMENT RESUME

ED 303 724 CG 021 422

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TITLE Faces of Neglect.
INSTITUTION Texas Univ., Austin. Hogg Foundation for Mental Health.
PUB DATE 88
NOTE 26p.
AVAILABLE FROM Hogg Foundation for Mental Health, Texas University, P.O. Box 7998, University Station, Austin, TX 78713-7998.
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS *Caregivers; Case Studies; *Elder Abuse; *Family Caregivers; Family Problems; *Individual Needs; *Older Adults; Parent Child Relationship
IDENTIFIERS *Elder Neglect

ABSTRACT

The family is the primary source of support and caregiving for the frail, dependent elder, providing emotional support, logistical services, supplemental finances, and the link to the outside community for the homebound elder. The caregiving systems of 84 of Texas's Adult Protective Services' (APS) cases were examined. The definition of neglect that was used was neutral in attribution, referring neither to self nor caregiver responsibility nor to active or passive intention. Case studies examined what caseworkers found entering the situation; what intervention was chosen; how the elder and family responded; and what the outcome was. The neglected elder is one whose needs are not adequately met in one or more of these areas: personal care, nutrition, medical care, or condition of the environment. Whether inadequate care was due to self-neglect or caregiver neglect was not always easy to determine. Case analyses resulted in five profiles of situations and problems that describe why caregiving systems seemed to fail: (1) the caregivers were overwhelmed; (2) the elder refused care; (3) caregivers were more interested in their own gain than in the elder's welfare; (4) the caregiving system was dysfunctional due to poor relationships or difficult personalities; and (5) the elder was alone and had no one on whom to rely. Interventions ranged from caregiver support; emergency action, including forced removal; and general assistance. Caseworkers felt the most critical need was for greater resources, increasing what was already in place, more emergency funds, and more medical services. The need for more preventive services was also emphasized. Abuse and neglect were thought to be the result of multifaceted problems which required multiagency resolution. (ABL)

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Faces of Neglect

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"I am one of the old, the frail, and the neglected, the multitude of the elderly, unnoticed and unknown by outsiders.

"My voice is often lost in the din of automobiles racing, radios shouting, lawn mowers grunting.

"I am alone, even in my daughter's house or with my husband, alone with my pain and confusion and lack of strength.

"Power has gone from me, pouring from my body like water draining from a ditch.

"Sometimes I forget to eat or to clean myself or my house. I fail to stay in the middle of life."

Foreword

Since 1981, the Adult Protective Services division of the Texas Department of Human Services has had the statutory responsibility and authority to provide services to aged and disabled adults who are victims of abuse, neglect, and exploitation. The number of reports increased from 3,300 in 1982 to over 20,000 in 1988. Most of the cases processed involved some form of neglect.

Working with individuals who have no one to give adequate care and who are no longer able to care for themselves presents some of the most difficult dilemmas for the Adult Protective Services worker and requires the most finely tuned skills and expertise.

The Adult Protective Services worker must give relentless attention to the principle of the right to self-determination, including the individual's "freedom to folly." This fundamental consideration must always weigh heavily against any involuntary intervention in the name of safety.

The APS worker must be skilled at evaluating an individual's ability to understand the consequences of his or her decisions. The worker must be able to measure the likelihood and immediacy of life-threatening consequences in order to decide whether to intervene.

The Adult Protective Services worker must be prepared to withstand the pressure and outrage of the community which is demanding that something be done despite the wishes of the individual. And, finally, the Adult Protective Services worker must be prepared to take drastic steps, sometimes over the protests and threats of irate family members, when the individual clearly lacks the capacity to make choices and the situation is life-threatening.

Providing protection to vulnerable adults is a challenging and exhausting responsibility. *Faces of Neglect* sheds an objective light on what has been called a "hidden scandal" and provides insight that can effect a positive change in the delivery of services to aged and disabled victims.

The Adult Protective Services recognizes the authors of this article for their dedication to improving the lives of elderly and disabled persons. Their faithful support and guidance have been invaluable to the program.

Judy Rouse
Adult Protective Services Administrator
Texas Department of Human Services

Preface

Neglect wears many faces. It may be seen in a child with matted hair and filthy clothes . . . or an animal starving in a pen.

Neglect wears many faces. It may be silent and invisible—or as noisy as a hungry infant.

It can occur to spouses who are abused both physically and psychologically. In recent years it has become visible among the frail elderly who may be neglected by family or other caregivers or who may neglect themselves. Many times the caregiving spouse grows too old and feeble to care for the other, and neglect evolves for both of them.

The whispered voices and vague faces, which are heard and seen most frequently by concerned professionals, provided impetus for a study on Family Neglect and Self Neglect. The issue of elder abuse has surfaced in recent years, but the more subtle issue of neglect, whether by self or others, has remained largely unstudied. The multiple contributing factors negate simplistic answers. Elder abuse has been the subject of much research. The issue of neglect has received much less notice.

Concerned with how to learn more about neglect, Dr. Bettina Adelberg Dubin, Jacqueline Lelong, Reuben Garcia, and Dr. Richard Mowsesian decided to undertake a study on this relatively unknown aspect of elderly problems. They approached the Texas Department of Human Services and asked for permission to read case material from the Adult Protective Services (APS). A request to the Hogg Foundation for Mental Health for partial funding to conduct the study was answered positively. The team went to work.

Some 260 cases were reviewed. The investigators knew that the cases which were most detailed and which showed the most persistent follow-through were probably written by the finest case workers in the field; the less competent probably offered little written documentation. Still they felt that the material offered startling and impressive information about why frail elderly people neglect themselves and what strategies could be used to help them. They found that the causes ranged from lack of strength to lack of funds or lack of information—or, often, from lack of care by family and other support systems.

The findings show that neglect happens three times as frequently as abuse or exploitation. Yet neglect brings with it its own dilemmas. Where does self-determination end and self-neglect begin? Is the old woman who is living a bizarre lifestyle in a small apartment so cluttered that there remains only a small path from one room to another a victim of neglect? Or, if her thinking is clear, does she have the right to choose to spend her remaining days amid the stacks of empty baby food jars and old newspapers?

And—who has the right to make the decision? Would she live a more enjoyable life in strange surroundings where the room was clean and the food well prepared? That dilemma is one which troubles caregivers who see the needs of many of the frail elderly but who walk the thin line between caring for their physical necessities and tending to their psychological wants.

Sometimes it is hard to sort out the victim—the caregiver or the elder.

The report on the study "Family Neglect and Self Neglect" is available for $12.00 from Family Eldercare, Inc., P.O. Box 2689, Austin, Texas 78755.

Introduction

Police are called to an apartment where an old woman lies dead on the floor. She is filthy, her open mouth pocketing moldy food. Human feces are all around her.

Her body goes to the morgue, and her Airman son goes to jail. The newspapers spread the story of neglect on the front page. The town is outraged.

But look deeper. The son was 25 years old, an only child, who brought his mother to his apartment because her sister, with whom she had been living in another state, had died. He attempted to care for her but had not reckoned with her senility. If he brought her food, she kept it in her mouth for days. She was incontinent, refused to drink liquids, attempted to wander on the streets.

He contacted the city services he could find. Home health aides were brought in. The mother chased them out.

And then, after some weeks, she died, like an animal on the floor.

Was she the victim of self-neglect, family neglect, or professional neglect? Where were the community resources for her and her son?

Neglect and abuse become the concern of everyone. Because no man is an island, the welfare of one person becomes the responsibility of the many. Social neglect is a collective problem.

Does neglect happen among the wealthy or only among those who are deprived financially? Can the oil baron surround himself with enough support systems to maintain him even though he is senile and incontinent? But what if he lives alone in a large house where the weeds have taken over the yard and the filth has invaded the palatial home? The neighbors say he never leaves the house in the daytime. His skin hangs from him. He won't let anyone in the front door. Will this self-neglect be tolerated? What if he refuses help in the form of cleaning assistance or hot meals? Is this self-determination or self-neglect?

Neglect wears many faces. It may show in the oilman just described. Or it may occur across town in the small home now crowded with Gramma plus the three children. The weight of care impacts on them all. They try to meet the grandmother's needs, but they become worn down. She wanders the house all day while they are at school or work. If they leave food for her, she forgets to eat it or spills it on the floor. If they clean her in the morning, she is filthy by the time they return.

The children become resentful. The husband gets belligerent. Gramma grows worse, and daughter becomes overwhelmed and exhausted by the demands of caring for her mother.

Soon they all quit trying. Everyone stays away from home as much as possible. Gramma is neglected.

Neglect may cut across financial and ethnic lines. It may result from indifference or exhaustion or resistance from the elder.

A population growing old demands attention. With a projected 30 million people age 65 or older by the year 2000 and with the 85+ age group as the fastest-growing in this country, it becomes evident that neglect by self, family, or professionals will surface as a major issue in the future.

Little has been known about the dynamics of family neglect and self-neglect. Recognition of the extent and complexities is surfacing only now. The general public remains unaware, and service providers do not have full understanding of this family dysfunction. The circle of victims of family violence and neglect now includes the elder as well as the child and battered spouse.

Focus on Caregiving

The family is the primary source of support and caregiving for the frail, dependent elder. It provides the emotional support, the logistical services, the supplemental finances, and the link to the outside community for the homebound elder. The great majority of families accept the responsibility of this care at a time of illness or disability.

The myth that families no longer take care of their aging parents as they did in "the good old days" persists, yet it is not true. On the contrary, Elaine Brody (1985), a noted researcher in family care of the elderly, claims that now adult children provide more difficult care to more elders over much longer periods of time than ever before. Yet most are ill prepared to endure the siege of long-term care, and the increasing strains of this care take a heavy toll on all concerned.

The caregiving system was the focus of an in-depth analysis by Dr. Dubin of 84 of the Adult Protective Services' cases. Caregivers include members of the family, friends and neighbors if they are involved in care, those providing paid services, and the elder. It is assumed that elders are involved in some self-care, unless they are severely mentally impaired.

The definition of neglect that is used is neutral in attribution, referring neither to self nor caregiver responsibility nor to active or passive intention. A state of neglect is considered to exist when the basic needs of the elder exceed what is being provided. The deficiencies in these cases resulted in situations that were reported to the state's Adult Protective Services.

A case study approach was used in order to maintain the integrity of each story. Case readings incorporated all materials in the Adult Protective Services file—the intake reports, investigative reports, and daily narratives. For each of the 84 cases, 13 questions addressed the following details: what the caseworkers found upon entering the situation, what intervention was chosen, how the elder and family responded, and what the outcome was.

Thus the method of case analysis was descriptive—to examine what kinds of situations emerged, their associated problems, what roles family members played, and how caseworkers handled these situations. Since these cases did not comprise a thoroughly randomized sample, they cannot be considered representative of the population of the state.

Once cases were classified according to similarity of situations, these categories were presented to Adult Protective Service caseworkers from six cities. These caseworker interviews tested the premises of category classification and enriched the profiles through their feedback, resulting in the refinement of the profiles of neglect.

The neglected elder is one whose needs are not adequately met in one or more of these areas: personal care, nutrition, medical care, or condition of the environment. As a result, the person may be found disoriented, in very poor health, with bed sores, in dirty clothes, unbathed, living in filthy conditions, among human and animal waste and insect infestations. In addition, the elder may have been reported as exhibiting bizarre behaviors such as wandering into other people's homes, flagging down traffic, refusing to wear clothes, and other manifestations.

About half (48.8%) of the APS cases were referred by professionals; the other reported half was equally apportioned among family members, friends, neighbors, and concerned citizens. A home health aide states that her 92-year-old patient, who weighs 350 pounds and suffers from heart problems, refuses to wear clothes or take medication and complains about little black beings invading her body. A neighbor calls about an 87-year-old living in a filthy house smelling strongly of cat waste. Neighbors claim her house needs cleaning and her clothes need laundering. They have helped with errands because she has no living relative and no friends.

Family members who report are usually at the point of not knowing what to do about the elder. They sometimes turn to Adult Protective Services hoping the agency will intervene to communicate with the elder when they cannot, take charge of the elder because relatives live out of town, convince another family member to handle a responsibility differently, or have the elder removed from the care of another relative.

A daughter reports that her stepfather is not providing adequately for her mentally impaired mother's nutrition, bathing, or medical attention. He will not listen to her. A son reports that his 92-year-old father is suffering from diarrhea and dehydration. He cannot convince him to get medical attention. When he earlier summoned Emergency Medical Services, the father had refused to go to the hospital.

Whether inadequate care is due to self-neglect or caregiver neglect is not always easy to determine. In some cases, the elder may refuse to eat or take medication offered by the family. In other cases, the caregivers are also elderly or ill, doing the best they can under difficult circum-

stances. Sometimes the elder is belligerent and runs off whatever hired help the family may have put in place. Rather than blaming either the caregiver or the elder, the professionals chose to assess different caregiving systems in order to determine what it is about them that causes difficulty in providing adequately for the elder.

Case analyses resulted in five profiles of situations and problems that describe why their caregiving systems seemed to fail:

- because the caregivers were overwhelmed
- because the elder refused care
- because the caregivers were more interested in their own gain than in the elder's welfare
- because the caregiving system was dysfunctional due to poor relationships or difficult personalities
- because the elder was alone and had no one on whom to rely

The following section will examine the situations within each of these major categories and describe the various possible approaches and interventions. Reactions to the study from practitioners who serve the frail, dependent elder are provided in the section "Conclusions."

Profiles of Neglect and Responses

The Overwhelmed Caregiving System

Mr. T was a 79-year-old man living with his daughter and her family in a small overcrowded house. He had suffered a head injury many years ago at his job. He still experienced headaches and had some trouble ambulating. Because his daughter worked, he spent all day alone, mostly sleeping. He was obviously depressed, not eating well when alone, and he was becoming more frail as a result. A neighbor reported his situation to Adult Protective Services.

In the overwhelmed caregiving system, family members, friends, or paid providers are involved in providing care and maintaining responsibility, but they cannot do all that is necessary. An abrupt change may occur such as hospitalization of the caregiver or a continuous deterioration may reach a critical level where the functioning of the elder or the livability of the environment is affected.

Examples of the Overwhelmed Caregiving category are:

The adult child who lives out of town. Reports notify the son or daughter of the elder's strange behavior. Or word comes that a parent's physical condition has worsened to a point that it requires daily attention.

The adult child who provides care for the elder in the home but also holds a job and must be away during the day.

The caregiver or the elder who refuses to consider nursing home placement although such extensive care is needed.

Families for whom the cost of needed nursing home care is too high.

Elderly spouses serving as caregivers who find the cost of supportive community services too high, but who cannot meet the needs of frail spouses without assistance.

A spouse or family that is unaware of supportive services or how to access them.

A dependent adult child, often elderly, living in the elder's home. If mentally retarded or mentally ill, the younger member is not only incapable of providing care but may also require care.

Families that have always lived close to the edge of survival, eeking out a meager existence, that are put over the line of adequate coping by the frailty of the elder.

Interventions

Interventions with the overwhelmed caregiving system generally had the most successful outcomes and the lowest resurfacing rate. Most everyone in these situations accepted and received assistance. In most cases a caregiver support system was already in place and open to betterment. The outcome was usually an obvious improvement in the physical and mental health of the elder—even where mental impairment was present.

The caseworker's job was found to entail, first, many discussions on what needed to be done and information about what service options were available and how these could be obtained. Caseworkers also served as intermediary, offering suggestions from one family member to another.

The caseworker spoke with medical personnel and communicated to family members or providers how medication should be administered or other treatments applied. One counseled a husband about Alzheimer's disease. Another called a meeting with neighbors caregivers and a

friend of the family to discuss what needs existed. In one family, the husband heeded the caseworker's advice regarding his wife's care where previously he had refused similar advice from his stepdaughter.

Intervention involved arranging services that allowed the elder to remain within the community. These assists included household repairs and clean up and, sometimes, plans for home health providers. Giving information about day care was a particularly successful intervention because participation in such a program did not disrupt the existing caregiving system and did provide great benefit to both the elder and the family.

Often intervention in the overwhelmed system involved a change in the living situation of the elder. This sometimes meant a move to the home of an adult child or from one family member's home to another or to supervised living facilities or public housing. Some temporary placements were necessary in the VA hospital, the state hospital, or a nursing home. Permanent moves to nursing homes occurred. In most cases, these elders were relieved to be out of the overwhelmed caregiver predicament or were too confused to mind the change.

Both elders and caregivers in this category were generally cooperative and grateful for improvements resulting from intervention. Two prime exceptions were:

. . . elderly persons suffering mental or sensory impairment for whom change was especially frightening, signifying for them the loss of control over their own lives and

. . . family members who viewed intervention as putting greater pressure upon them without any additional help. In this dilemma were middle-income families who did not qualify for low-cost services but could not afford to pay standard rates or for nursing home costs.

The Elder Refuses Assistance

An 82-year-old woman, bedfast after having suffered a broken hip, lived in filth. She was incontinent. Cat waste was everywhere. The bathroom plumbing was broken. She was being cared for by her husband who passively submitted to his wife's wishes that things remain as they were with no interference from anyone. The woman's daughter reported the case.

In this category are (a) elders for whom family or friends provide or are willing to provide care yet the elder refuses it or (b) elders living

alone in poor circumstances with no one looking after them, yet they refuse outside intervention. They do not want medical attention, medication, household clean-up, sometimes even food.

Six patterns emerged from the case studies and the apparent motivations of these resistant elders.

Elders near death. These were old, frail, ill persons who did not want to be removed from home or have heroic efforts made. Reports to Adult Protective Services were usually from adult children who wanted more done for the parent than the parent wanted.

Despairing elders. The elders in this circumstance were depressed by losses that could not be rectified. Some had terminal illness, some were bedridden. Some had lost the last person close to them. Change would require an adjustment which they were unwilling to make. All of them wanted only to die, and by refusing aid they were committing slow suicide.

Wrongly despairing elders. Though solutions for their difficulties might well be possible, depressed elders saw their problems as overwhelming. The subjects resisting were too depressed—sometimes too angry—to accept that anyone or anything could improve their situations. Sometimes depression was a result of a physical disorder, a nutritional imbalance or medication and, thus, it was easily treatable. Others had ideas that a family relationship or living arrangement was beyond hope.

Jane Thibaut (1984) refers to similar noncompliant behavior patterns as "indirect self-destructive behavior." She believes they may function as problem-solving behaviors—attempts to call attention to one's problems—by elders who feel inept at confronting or handling their problems themselves. Thibaut's description suggests a personality style of some elders as opposed to the situational physical attribution suggested above. Either or both could be operating for the resistant elder.

Denying elders. These elders were hanging onto the status quo because they did not accept their increasing lack of functional ability. Accepting help would mean acknowledging the problem and having to face dreaded alternatives such as nursing home placement. Largely, denying elders were those who realized that they were not doing as well as before, but they denied problems rather than have them acknowledged. For some elders, this stance allowed them a sense of control when they otherwise felt it slipping.

A subgroup of Denying Elders might be *Adapted Elders*, referring to those whose environmental and physical conditions have changed grad-

ually enough to allow the elder to adapt. They may no longer notice deterioration that an outsider would find startling. Other researchers (Clark et al, 1975; Cornwall, 1981) have found many such elders to be of above average intelligence and of professional stature, with personal and home care having a low priority through their lifetimes.

In addition, some elders suffering from mental illness resisted intervention because they were unable to see their behavior or situations as abnormal. Though capable of lucidity at times, one might also claim to see buses coming through the wall or live in a car strewn with feces. They may have resisted intervention out of fear and because they did not understand the need. Where gentle and persistent confrontation eventually might have influenced a denying elder, it would not even have made any sense to an elder who was mentally ill.

Mistrusting elders. These persons were particularly sensitive to scrutiny or control by anyone—especially the state, the welfare department, or other "authorities." Alcoholic women were cited by one caseworker as particularly mistrusting because they did not want their drinking to be discovered. Others in this category tended to be fiercely independent people. Some trusted only the family, only a spouse, or only one friend. This group includes elders who were primarily protective about their finances. They refused any review of their financial status, and if intervention required such review, they would forego intervention.

Prideful elders and caregivers. This category included elders who not only had prided themselves on their accomplishments and or self-sufficiency but often had held some stature and respect in the community. Doctors, lawyers, and teachers, for example, who had become vulnerable physically, mentally, and financially, found it hard to ask for and accept help, especially if it seemed like charity.

There were also caregivers who refused help when they felt it was a challenge to their competency or devotion. Horrified that anyone would report them and ashamed to be offered help, their first response was likely to be angry and defensive.

Interventions

Intervention with resistant elders was likely to involve taking emergency action—hospitalization, nursing home placement, movement toward guardianship—or nothing at all because of the elder's continued resis-

tance. Of prime importance was awareness of the sensitivity of each individual's desire for self-determination. Where a caseworker was able to influence a resistant elder or caregiver most successfully, it was accomplished by first establishing trust and allying with the person, focusing on the rapport rather than the problem. The more personal the role the caseworker took—going with the client to the doctor or being present when clean-up people came, for instance—the better were results. Interventions and their outcomes varied with the reasons for resistance:

Near death. Wishes of the elder were respected. Caseworkers offered information about forced removal but left the decision to the family or elder.

Despairing elders. Interventions were found to make little difference. When hospitalization was forced or pushed, the elder later returned home to renew the earlier stance. Guardianship became necessary for some.

Wrongly despairing elders. Interventions, whether forced or accepted, did eventually bring good response. Improvement in physical health lifted depression for some. Personal communication—arranged by a caseworker—from an estranged child to a difficult and lonely old father had a significant effect on reducing the father's misery.

Denying elders. Interventions had to be paced; forcing could result in deeper entrenchment for the elder. Caseworkers endeavored to gain trust, to be kind yet confrontive, to induce the family to confront gently. Where the elder's denial could quickly become self-destructive, it was necessary to allow the situation to worsen to a point where assistance was accepted or to seek court orders and guardianship.

Mistrusting elders. Most of these persons were unlikely to accept assistance though some were willing to take a phone number for future reference. (In two cases, the elder actually used the number to call.) A few, primarily those with no supportive family, responded to a strong alliance with a caseworker of "us" against "them." Some agreed to action (clean-up, repairs, hospitalization) only in response to warnings of calling in the health department or obtaining court orders. Others acquiesced when their orientation fell to a point where they were no longer aware of circumstances.

Prideful elders and caregivers. Both of these groups tended to become cooperative when personal attention was given to their specific needs and wishes. One caseworker had observed an elderly doctor as he

sterilized his can of food and the opener. She impressed him by doing the same when she prepared food for him. Once her strenuous effort was acknowledged, the daughter of an elderly woman with bedsores finally admitted that she could not manage the care her mother required.

Further approaches to intervention involved offering alternatives that were less intrusive than formalized services yet built trust and reaching the resistant elder through significant others. Generally, however, work with families that were reluctant to counter an elder's demands or who were generally passive tended to be short-lived. Many families feared the responsibility of countering their relatives' wishes.

The category of elder refusing assistance had the highest mortality rate of those in the study. Caseworkers and caregivers all had their most difficult judgments in this category—whether to push intervention, when, and how far.

The Self-Interested Caregiver

An 84-year-old mentally impaired woman was removed from a nursing home to be cared for by her great-niece. The care proved to be inadequate as evidenced by the deteriorated condition of the elder. The great-niece appeared more interested in the aunt's Social Security check. It was learned that she had been indicted previously for attempting to defraud public agencies.

This is the one category in which guilt is implied, when the caregiver's gains appear to outweigh benefits to the elder. Some elders in this situation still prefer these circumstances to being placed in a nursing home.

Interventions

These interventions were simple and effective. In all cases, the elder was removed from care or responsibility of the caregiver. Where the elder had been living with the caregiver, hospitalization was usually required initially with nursing home placement to follow. The outcome was improved care for all the elders. Those with any awareness of their situation expressed appreciation for the change.

The response of caregivers in this category was hostile. All, however, complied under pressure.

A 69-year-old man lived alone but was managing poorly. He could not ambulate well, and he fell easily. He had memory and lucidity problems as well as poor nutrition. His family lived in the same town, but his children claimed he had been an abusive father when they were young and could still be so. They wanted him to have help, but they, themselves, wanted nothing to do with him.

Dysfunction in caregiving situations may stem from a number of origins. Difficult personalities of the elder or the caregiver are one such origin, as are conflicted family relationships. Elders may have been violent at worst and uncooperative at best. They may have driven away help or careproviders sent in. Some had been evicted by nursing homes. Some caregivers, too, had traits ranging from hostile and aggressive to immature and parasitic.

Dysfunction due to alcohol abuse by caregiver or elder falls into this category, as well. Because many of the elders who drank were not trustworthy about abstinence, constant supervision was necessary. Alcohol also reduced competency of caregivers and increased their own need. An alcoholic family that perhaps "got by" earlier could not respond adequately to the needs of a dependent elder.

In cases of conflicted and rivalrous relationships, inadequate care was sometimes the result of arguments among family members and or elders. In more estranged families, ties may always have been weak (i.e., some elders had abandoned the children when they were young) or may have become weakened by time and distance. Sometimes the bonds were damaged by too many years of caregiving.

Interventions

The best arrangement for families with difficult relationships appeared to be where someone else provided care but family members still showed some concern. Sometimes the caregiver came from ranks of more distant relatives who had less historical—and less personal—involvement with the elder. When an elder's difficult personality was exacerbated by mental impairment, day care was needed and possibly nursing home placement. When drinking was a problem, monitoring by a full-time provider or supervised living was required.

Generally, elders in a dysfunctional caregiving system or those with trying personalities were difficult to help. Caseworkers had to provide more assistance because elders and families contributed little. Rarely

was a caseworker's single attempt with a new caregiving arrangement sufficient. Repeated efforts were necessary because either the elder or other family members failed to follow through on interventions.

Care providers could only rarely withstand the behavior of an elder who was seriously troublesome and perhaps violent. Nursing home placement then became a last resort.

The Elder Alone (An Overwhelmed Caregiving System of One)

An 82-year-old woman lived alone in a filthy, odorous house with many animals. She suffered from heart disease and arthritis. The elder was thin and weak but mentally lucid. Her absence was reported by a clerk at the nearby food store who said she had not been in for groceries for a while. She had stated several times that she was getting by with the help she was presently receiving and that she did not want any additional assistance.

Elders in this category are those who have no one on whom to rely when they are unable to take care of their own basic needs. These are people alone because they have no sons or daughters or because they outlived relatives and friends or because close members of their own generation are also elderly and limited in activities or because, as suspicious loners over the years, they shut themselves off from others.

Most of the elders alone neglected themselves out of ignorance and confusion about where to turn. Some of them had neighbors who assisted now and then. However, it was often these same neighbors who notified Adult Protective Services of problems, attempting to relieve their own burden of responsibility.

Some of these elders could more aptly be considered resistant since their living situations (leaking roofs, badly soiled bedding, and such) were becoming increasingly dangerous and yet they resisted intervention.

Interventions

Interventions were highly successful when the elders would accept assistance. Although depression was noted in these cases, it was due to circumstances that Adult Protective Services could confront and ease. These cases usually entailed a great number of tasks for the caseworker; though there were few others to help, there was also no one to impede intervention. Some help, in fact, did come from concerned neighbors

who were willing to provide transportation to the doctor, bring food, monitor the situation, and report to APS.

Some elders in this category would never accept intervention. The caseworkers seemed to have little impact on the elderly with no significant others who were still physically functional though living in a deteriorated environment.

Conclusions

Suggestions by Adult Protective Services caseworkers who were asked about improving the program spotlighted three issues: additional resources, change in the process itself, and public education.

In their opinion the most critical need was for greater resources—an increase in what was already in place, more emergency funds, and more medical services. In addition, the need for new preventive services was emphasized—such as emergency shelters and volunteer guardians.

They also agreed in general that abuse and neglect are the result of multifaceted problems which will require a multiagency resolution. It was felt that the need for interagency involvement goes beyond the role of the caseworker. Collaborative efforts are long overdue at supervisory and administrative levels and are an essential ingredient in the long-term management of the chronic, hard-core cases.

A paramount concern of caseworkers was the lack of understanding of the limitations of the role of Adult Protective Services among the general public and within professional ranks. The practitioners called for public education presenting the major issues of mental incapacity and self-determination, clarifying the investigatory and case management role of Adult Protective Services, and clearly identifying the conditions and situations appropriate for their intervention. Ignorance of these issues results in unrealistic expectations on the part of professionals and the community. Frustrations born of these unrealistic expectations aggravate an already overloaded response system and forestall the teamwork necessary to address this complex problem of abuse and neglect.

A second group of practitioners was involved in assessing the findings of the study in light of their own professional experiences. Twenty-two persons, representing a wide range of agencies serving the elderly in Austin, Texas, formed a Community Action Committee which responded with recommendations for action against abuse and neglect of the elderly. Members agreed that a comprehensive range of services, with case management coordinated among the provider agencies, is essential. In light of the lack of funding resources at the time, the committee focused on early interventions which would prove less costly in human suffering as well as in money.

Recommendations of the committee covered a wide range of preventive measures. Defending the vulnerable elder from abuse and neglect involves activities such as educating the public, training service providers who come in contact with the elderly, and developing "buddy" systems in retirement facilities and "user-friendly" environments for the elderly. Housing especially designed to promote independence and facilitate self-care would decrease the likelihood of self-neglect, the group agreed.

Preventive interventions to protect high-risk elders include a team approach for difficult or resurfacing cases. Until a case management system can be instituted, a coordinated effort among the key provider agencies is needed. What often occurs among cooperative caseworkers, mental health workers, and public health nurses must be formalized by policy makers and facilitated by supervisors. Case conferences often expedite service and clarify objectives.

In-home services must be made more affordable for elders who are recuperating after hospitalization or who are candidates for a nursing home. Expansion of badly needed services such as home-delivered meals, homemaker services, and transportation is essential to help elders remain at home with dignity. Supportive services for family caregivers are recognized and appreciated as preventive interventions against abuse and neglect. Respite care must also be affordable as well as suitable to the various needs of families.

Remedial interventions in cases of abuse and neglect require an adequately staffed Adult Protective Services unit. The use of case aides could lighten and spread responsibility for routine tasks. Trained volunteers could assume the friendly visitor role or become representative payee or help with money management or, in some instances, serve as guardians.

It is noteworthy that the recommendations proposed by the Community Action Committee construct a comprehensive plan of community care services. This is not surprising, yet the realization that the lack of these services can render an elder helpless against certain events does place an urgency on the argument. Affordable community care services are the best defense. They are certainly the hands-down choice of the elderly.

Realization of the role of continual deterioration in the problem of neglect points to the need for interventions that can retard, halt, or even reverse such deterioration process. Many times internal resources can be reinstated to facilitate independence. Interventions that can provide consistent supportive services over time should be implemented in order to avert chronic self-neglect. In fact, the consistency of contact may be more important than the extent of help offered. For elders who become disoriented or paranoid, the consistent attention of an interested person can do a great deal to break through the isolation that breeds such problems. Where an elder refuses assistance, regular monitoring is recommended.

Increasing the public awareness of what to expect with advanced age and how best to respond—whether as family members, friends, neighbors, or professionals—can work on a large scale to reduce elder neglect. The unwillingness of many elderly to accept aid reflects society's widespread denial of the fragility of old age and the need to recognize and prepare for it. People fear the dependence it imposes and the interdependence it requires.

Once informed, the public cannot hide behind fear and ignorance. Public policy must take into account the needs of an increasingly vulnerable portion of the population—those above 75 years old. Such policy must not deny them the basic services for their health and well-being. Communities must be held accountable for social neglect, a significant factor contributing to self- and family neglect of the elderly.

Epilogue

Neglect wears many faces
So do the forces which help
Sometimes a caring neighbor sees the need and tries to fill it
Or a loving family member might be able to make positive alterations in lifestyle
A determined caseworker may effect means of helping the frail elderly person

Just as neglect wears many faces, so does help take on numerous guises. The important aspect is that of community awareness and community concern. That help can come from each of us.

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